Ethics Consultation

Summary: An empirical program of research to study how clinicians handle ethical dilemmas and how ethics consultation contributes to their resolution.

Section: Ethics and Health Policy – Unit on Bedside Ethics

Principal Investigator: Marion Danis, M.D.

Collaborators:

Bioethics	Gordon DuVal, S.J.D. Christine Grady, R.N., Ph.D. Samia Hurst, M.D. Connie Ulrich, R.N., Ph.D.
Other NIH Researchers	Adrienne Farrar, MSW, D.S.W.
Non-NIH Researchers	Brian Clarridge, Ph.D., Center for Survey Research Michael Fetters, M.D. Gary Gensler, MA, EMMES Corporation Laura Hanson, M.D. Patricia O'Donnell, M.S.W., D.S.W. Carol Taylor, R.N., Ph.D.

Background:

Ethical dilemmas commonly arise in the course of clinical practice. Empirical studies of inpatient and outpatient practice suggest that they arise in 15 to 20 percent of clinical encounters. Over the last several decades, ethics consultation has evolved as a means of assisting clinicians who are perplexed about how to best approach ethical problems. Indeed, hospitals in the United States are mandated by the Joint Commission for Accreditation of Healthcare Organizations to maintain some mechanism to resolve ethics issues, and a recent survey indicated that 81% of general hospitals in the U.S. have a consultation services. Yet ethics consultation is far from commonly sought out by many practitioners as indicated by a average rate of three consultations a year for surveyed consultants. One might argue that the frequent encounter of ethical issues in the course of their work necessitates that clinicians to be well versed in analyzing and handling ethical dilemmas on their own. Yet there has been little exploration of how clinicians respond to ethical dilemmas and how effective they consider the assistance of ethics consultants. Therefore, the objectives of this program of research are:

Objectives:

1. To describe and analyze how clinicians deal with ethical dilemmas they encounter in practice

2. To evaluate the contribution of ethics consultation to clinicians in resolving these dilemmas
3. To identify potential improvements in the function of ethics consultation services

Methods:

The empirical studies under this program of research have involved both qualitative and quantitative methods. These have included primary data collection using telephone and mailed surveys, as well as secondary data analysis and grounded theory. Survey methodology has included use of previously developed scales when available and the development of new survey instruments when appropriate including content validation, reliability testing, cognitive testing and piloting of questionnaires.

The initial core of this project has been a national, random telephone survey of general internists, oncologists and critical care/pulmonologists. The survey contained questions related to five domains: 1) description of the most difficult ethical dilemma encountered, the most recent ethical dilemma encountered, and the most recent ethical dilemma, if any, referred for ethics consultation; 2) the strategies employed by physicians to address ethical dilemmas; 3) experiences with ethics consultation including the need for, use of, and satisfaction with ethics consultation services; 4) socio-demographic, training and practice characteristics of physicians; and 5) training and experience with clinical ethics.

Short narratives of situations perceived as ethically difficult by the respondents (N= 310), were analyzed through a process of grounded theory. We aimed to understand the values and processes physicians report in dealing with ethical difficulties in situations when facing them without the help of a consultant. This qualitative analysis focused on three open-ended questions asked during the telephone interview. These questions asked respondents: 1) to tell the story of a recent ethical dilemma they had encountered in their work, 2) to name the main issue or issues raised by the case, and 3) to give an account of the decisions that were made as the situation unfolded.

Secondary analysis, while at the NIH, of a project funded by the Agency for Health Care and Policy Research (now the Agency for Healthcare Research and Quality, HS 06655) initiated prior to arrival at the NIH also contributes to the objectives of the current program of research . As part of a prospective investigation designed to understand the effect of patients and physicians preferences on the use and cost of care for terminally ill patients, we (qualitatively analyzed physicians' responses to open ended questions about handling situations when a patient did not want treatment that the physician considered beneficial or conversely when a patient requested a treatment that the physician considered non-beneficial.

While the predominant focus of this program of research has been an exploration of ethical dilemmas and ethics consultation in the clinical context, we have taken advantage of the unique setting of the Clinical Center at the NIH, to survey clinical investigators about the ethical dilemmas they encounter in the

course of their research as their assessment of ethics consultation. This survey was funded by the Division of Evaluation, Office of Science Policy of the NIH. We utilized a modified version of the survey instrument designed for the national survey of internists.

Results:

1. Internists' experiences with ethical dilemmas they encounter in practice

Ninety percent of responding internists (N=344) had recently encountered an ethical dilemma they could recall. The pattern of dilemmas they encountered varied by subspecialty. While end-of-life issues comprised at least half of the dilemmas for all respondents, general internists encountered justice related issues such as lack of health insurance in approximately a quarter of the dilemmas they recalled.

	Most Recent Ethical Dilemmas		
	General Internists	**Oncologists**	**Critical Care Specialists**
N	**82**	**119**	**113**
End of Life (%[1])	51[2]	55	78
Patient Autonomy	35[2]	36	61
Justice	23[2]	13	6
Conflicts Between Parties	35	34	38
Professional Conduct	11	8	4
Truth Telling	6[3]	12	4
Religious or Cultural Issues	6	4	4
Other	10	12	6

[1] Results add up to more than 100% because up to 3 codes were assigned to each response;
[2] Percentages differ among subspecialties, P<.01; [3] Percentages differ among specialties, P<.05;
[4] Other dilemmas involved abortion, genetic testing, substance abuse, research participation, and beneficence.

Physicians had a wide range of skills and available resources with which to address ethical problems. About a third of respondents (36%) had virtually no exposure to ethics grand rounds or courses while 17% had both exposure to grand rounds and ethics courses, felt confident about current ethics standards, and served on ethics committees.

In the qualitative analysis of physicians' narratives of situations perceived as ethically difficult, preliminary findings indicate the importance of avoiding or resolving conflict in such situations. Attempts to avoid or resolve conflict at times override other values often considered more important, such as respecting a patient's stated choices. Respecting the patient's autonomy and pursuing her objective best interest, which are often perceived as opposing goals, emerge

from this dataset as converging in a majority of the cases chosen by the respondents as ethically difficult.

Physician satisfaction with the decision made to resolve the most recent dilemma was 7.0 ± 3.0 (median 8) out of 10. When asked what would need to change for them to be more satisfied, the top four responses were: improving the decision making process to make it more efficient, inclusive, cooperative or communicative (26%); changing the knowledge, attitudes, or understanding of a clinician, patient or family member (19%); changing social or institutional policy, regulations, laws, insurance, or the cultural environment (19%); and changing clinical management or outcome (14%).

In our study of how physicians handled situations in which they disagree with patients about the benefits of an intervention, we found the following. For patients requests of non-beneficial treatments, physicians reported negotiating with and educating patients (71%), deferring to patient requests for benign or uncomplicated treatments (34%); convincing patients to forgo treatments (33%); refusing patient requests for non-beneficial treatment (22%); utilizing family influence (16%); not offering futile treatments (13%) and referring to other physicians for disputed care (9%). Potential harm (23%) and cost of treatment (18%) were reasons cited for withholding treatments. In response to patient refusals of beneficial treatments, physicians report as important: negotiating with patients (59%); convincing patients to receive treatment (41%); assessing patient competence (32%); utilizing family influence (27%); and referring to other physicians (21%). Physicians providing care at the end of life report strategies for respecting patient that reflect graduated degrees of accommodation tailored to the costliness and riskiness of requests; they are most accepting of patient requests for benign, technically easy, inexpensive, and medically effective treatments.

In our exploration of ethical dilemmas encountered by NIH researchers, they report that the most difficult issues they encounter relate to: informed consent (30%), clinical obligations during and after research participation (14%); ethics of study design (8%), involvement of children in research ((8%), truth telling and confidentiality (7%), justice in research particularly relating to uninsured patients ((4%), and termination of subject participation in research protocols (6%).

2. Evaluation of the contribution of ethics consultation

The national survey revealed interesting findings about what triggers a clinicians request for ethics consultation; and conversely about what makes clinicians hesitant to request ethics consultation.

Factors that Trigger Ethics Consult Requests	%
Wants help resolving a conflict	34.6
Wants help in making a decision of planning care	13.1
Wants help interacting with a difficult patient or family	10.0
Has emotional trigger	8.9
Has regulatory/legal/administrative reasons	7.9

Repeats previously described ethical problem	6.3
Wants help thinking through ethical issues	4.2
Someone else requested the ethics consult	3.7
Wants assistance with communication	3.1
Has concern about the fairness of a decision process or procedural issue	2.1
Anticipates a bad situation	1.1

Reasons for Hesitation in Using Ethics Consultation	%
Process is too time consuming	29
Consultations make things worse	15
Consultants are unqualified	11
Consultations are unhelpful	9
Solutions are not consistent with good practice	9
Difficult to access	3
Confidentiality concerns	3
Fear of reprisal	1
Other responses	22

Of particular note, physicians do not utilize ethics consultation in a uniform manner. Those with less training and skill in clinical ethics are the least likely to have access to and request ethics consultative advice.

Future Directions:

Planned studies are intended to broaden the type of health professionals we survey and compare the experience of ethical dilemmas and ethics consultation of U.S. physicians to that of internists in Europe. The workforce providing primary care to patients in the U.S. is increasingly comprised of non-physicians including physician assistants (PA) and nurse practitioners (NP). While they face many ethical dilemmas in their daily work, they appear to be insufficiently trained in ethics and are not substantial initiators of ethics consultation. In earlier survey by Ulrich, 50% of the nurse practitioner sample indicated no ethics coursework in their advanced practitioner programs and 58% indicated no ethics coursework in their basic professional preparation (2001 data). Thus a national survey is planned for physician assistants and nurse practitioners that will particularly focus on their perceptions of ethical issues in primary care practice.

Similarly, other professionals on the health care team encounter ethical dilemmas and have had insufficient training in ethics or access to ethics consultation. A study of nurses and social workers is currently planned. There is evidence that ethical stresses are a major determinant of their job satisfaction and retention. Yet evidence indicates that these health professionals are hesitant

to ask for ethics consultations. In piloting the questionnaire for this study we found that 26% of responding nurses and social workers did not seek ethics consultation for fear of reprisal. This is a crucial and understudied problem in clinical ethics. Those with ethical concerns may not be voicing them. This study will involve a national, random sample of nurses and social workers using a self-administered mailed survey.

Finally, much of the work surveying internists in the US is of interest to clinicians generally. Ethics consultation is at a more fledgling stage in Europe. Medical ethicists in Europe need systematic information about the ethical problems clinicians face as they plan ethics consultation services. The Department is initiating a survey of primary care physicians in four countries in Europe, including England, Switzerland, Italy and Norway. One of the more important features of this study is an exploration of the interaction of ethical issues at the bedside and policy level. A novel aspect of this study will be an exploration of the relationship of ethical issues at the individual practitioner level and the organizational level. Thus, physicians will be queried about the impact of policies on their work.

Publications:

DuVal G, Sartorius L, Clarridge B, Gensler G, Danis M. What triggers requests for ethics consults? Journal of Medical Ethics 2001;26:0-5.

Fetters M, Churchill LR, Danis M. Conflict resolution at the end of life. Crit Care Med 2001; 29:921-925.